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the 1981 White House Conference on Aging

Report of Technical Committee on FAMILY, SOCIAL SERVICES AND OTHER SUPPORT SYSTEMS

NOTE: The recommendations of this document are not recommendations of the 1981 White House Conference on Aging, or the Department of Health and Human Services. This document was prepared for the consideration of the Conference delegates. The delegates will develop their recommendations through the processes of their national meeting in late 1981.

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I. INTRODUCTION

The Technical Committee on Family, Social Services and Other Support Systems supports the adoption of public policy for the development of a comprehensive continuum of services available to older persons, without regard to income, minority status, geographic location or any other variables. The system should provide for the coordination of private and public resources and such linkages between formal and informal support systems in order to contribute to the well being and quality of life of older persons.

The focus of this report is on the older person as an individual and the sources of financial, psychological, and social supports that assist the individual to retain independence in the community to the greatest extent possible.

The family is defined here as a system of related and unrelated individuals, integrated by patterns of social relationships and mutual help.

The services system is composed of public and private agencies and programs that provide income maintenance, health and social services. Included in this definition are those aspects of service delivery that promote the well being of the older person.

Other support systems are defined as individuals and groups that provide services on an informal and "as needed" basis, such as friends, neighbors, and religious affiliates. They include members of the informal network who perform tasks requiring frequent contact, such a shopping, and who are the closet resource in time of crisis.

While these broad definitions provide a general frame of reference, there are many variations in the use of support systems among the aged population. The older person may depend upon the family, social services and/or other support systems based on cultural preferences, physical and mental health status, living arrangements, and chronological age.

Findings indicate continuance of strong family ties with special strengths among particular ethnic and racial groups. For the many older persons who have no living relatives, the social services system may provide the bulk of supports.

All three types of support systems - - - the family, social services, and informal support systems - - - are important in responding adequately to the needs of older persons.

The Technical Committee agreed that the following values provide the foundation for its policy recommendations.

II. VALUES

1. Older persons must be treated with dignity and respect under all circumstances.

2. Self-determination and the existence of choices and alternatives are essential for the well being of older persons.

3. Programs and policies should be responsive to individual and cultural differences among older people.

4. Older people should be guaranteed an income that makes possible the maintenance of dignity and health.

5. Services must be available, accessible, and acceptable to older adults.

6. Older people are a resource whose experience and knowledge should be used more effectively.

7. Family, friends, neighbors, and the community are essential to the well-being of older people.

8. Older people have the right to share in the decisions affecting their lives.

9. Linkages between the formal and informal support systems, and between the public and private sectors, are essential to assure access to services and quality of care for older people.

10. Older people have the right to live free of fear and discrimination.

11. Older persons should participate in the planning and administration of programs.

12. Priority should be give to those older persons in greatest need.

Such basic values must be evaluated in relation to differences in patterns of living among the older population.

III. TRENDS AND CHANGING PATTERNS OF LIVING

1. Most older people remain active, reasonably healthy, and independent.

2. The increase in the number of multigenerational families (as many as four and five generations), is expected to place added demands on the social service and health delivery systems in the future.

3. The greatest numerical increases among the older population during the next two decades will be: women, those 76 years of age and older, and ethnic and racial minorities. This has significant implications for the service delivery system, for the family, and for the allocation of resources.

4. There are increasing numbers of older people living alone, especially women. Those individuals living in the inner cities and in rural areas, are the most vulnerable.

5. The existing bias of health care delivery, which primarily reimburses for institutional care, continues to make it difficult for those individuals wishing to remain in their own homes.

6. The existing service delivery system is characterized by increasing complexity and fragmentation, and this may continue in the future unless significant changes are made in the organization, delivery and financing of services.

7. The increased longevity of older people has significant implications for the types of services provided to those with chronic health conditions and social problems. It also has major implications for the training and education of personnel serving older Americans.

8. The family will continue to provide the majority of direct services to older people.

9. The informal support system of family, friends, and neighbors will continue to be essential in assuring access to services, and in meeting the varied needs of older people.

10. Financial and economic resources of older persons will remain a key factor in determining their well-being.

11. The functional role of older adults in society will play a major role in determining their quality of life.

On the basis of the values, trends and changing patterns of living, the Technical Committee identified the following key issues for investigation and for the development of recommendations.

IV. KEY ISSUES

1. How can a comprehensive continuum of services be designed that includes both formal and informal supports, public and private agencies and resources, for meeting the needs of older people and their families?

2. What should be the governmental and non-governmental roles in meeting the current and future needs of older Americans?

3. How can public policy, programs and services strengthen and protect the role of families in fostering the continued independence of older people?

4. How can public policy provide for in-home and community-based services as an entitlement for older persons?

5. How can social services and other support systems be organized to assure access to and follow-up for needed services?

6. How can social service systems and benefit entitlement programs be implemented to insure responsiveness to the cultural and social differences found among older Americans?

7. How should public policy provide for adequate resources to assure the development of wellness programs for older people?

8. How can newer forms of service be more effectively designed and financed to meet the needs of older adults and their families?

9. How can older people be guaranteed an income adequate for the maintenance of health and dignity?

10. How can the disincentives in law and regulation, which discourage family support and service provision to older adults and their families, be eliminated?

V. THE CENTRAL THEME

The following diagram points up the central theme of this report--the interrelationships among the family, social services and other support systems in providing personal care and support services within the home and community. The older person is the core concern. He or she interacts with the family, social services and other supports to complete the picture. The relationship involves the continuous flow and interaction that contribute to individual well being.

Figure 1. The Older Person and the Support Systems

All three types of support systems within the community--the family, social services and informal support systems--are important in responding adequately to the needs of older persons. A discussion of each of these systems separately, with its strengths and weaknesses, forms the basis for the recommendations that propose a continuum of services system. Such a system must take into account cultural preferences, physical and mental health status, and geographic location. Illustrations of the services provided by each type of support system indicate major contributions and developments, but also gaps in service that presently impede achievement of the ultimate goal of maximum well being for each older individual.

VI. HISTORICAL AND CURRENT STATUS OF THE FAMILY, SOCIAL SERVICES AND OTHER SUPPORT SYSTEMS

A. Family

In the preindustrial era sometimes referred to as the "Golden Age", the older person usually lived with and received needed support from the family. Prior to 1900, over half of all females never married, or died before childbirth, or were widowed while their children were still young. Men rarely lived beyond the marriage of their second child.[1] Those who survived to old age rarely lived alone. In 1850, only one in ten persons over 65 was not the head of a household or the spouse of a head. By 1880, the figure was one in six and by 1970 it was one in four. This reflects the large number of older persons who head their own household, either living alone, or sharing accommodations with relatives or nonrelatives. Today, the general welfare of older people has improved sufficiently to allow many to maintain independence. Living independently is the preference of the great majority of older persons - - physically apart from children but not far away.[2] Inter-generational relationships tend to be based on cooperation and mutual exchange, with neither generation subject to the authority of the other.

The advantages of satisfactory health and increased financial resources make it possible for many elderly to maintain their independence in living arrangements of their choice. But there are many older persons who are poor or near poor; many with serious physical problems; many who are too frail to manage without family or other assistance; many who have special needs related to race or ethnic background. For large numbers of older individuals, the family is still looked to as the major source of support. A feature unique to families is the kind of help they can give. Most families are flexible in that they can act and react to crisis situations even when they often cannot provide long-term assistance.

Trends in fertility and mortality have also altered the family composition of older people. Increased longevity has brought about the phenomenon of the multigenerational family. Almost half of all persons aged 65 and over have great-grandchildren,[3] and increasingly the children of the oldest generation are themselves aged 65 and over.[4]

Other socio-demographic trends that affect family bonds are divorce and remarriage. While this trend is most evident in the younger population, it will certainly affect older persons in the future. The ramifications of divorce and remarriage, ties between former in-laws, and the relationships between grandparents and grandchildren have been little researched to date. Most people who divorce also remarry, although the

remarriage rate has been declining. It seems reasonable to assume that a divorce in a family will involve all generations in an expanded set of relationships which may then influence older people and their family support systems.

Another trend that influences the family as support system is the rising participation of women in the labor force. This trend may have the positive effect of providing future generations of older women with more retirement income, plus additional skills.[5] It will make these women more independent and enhance ties between older women and their children. In terms of family support, however, daughters may have less time to assist older parents. The extent of the effects on the lives of older persons remains the purview of research.

There is little doubt that the family as we know it today will survive. The question is, will the family care for its older members as they require increasing support from others. The older segment of the population is growing faster than any other and the oldest group (75 and over) is the fastest growing.

The result is more and more families with aging parents and grandparents. Given the multigenerational family, (rapidly growing to four and often five generations), the influence of marriage, divorce, role changes and redefinitions of family functions, the effects on the family will become increasingly severe. Provision of services, programs, and financial incentives will make it much more feasible for the average family to maintain and fulfill its historic role of primary caregiver.

A flexible approach, dependent on circumstances, should suggest the ways in which the family can be assisted in its ongoing role. For older persons who care for relatives, day care, respite care, homemaker-home health aide services, and other opportunities for brief periods away from the older person should be provided. Cash incentives such as older-care vouchers, cash subsidies, subsides for time lost from work should be considered. Tax allowances for families, comparable to those now provided for care of children, should be explored. Certainly current disincentives in legislation and policy, discouraging families from providing needed support and care, should be eliminated. For those who do not have relatives, other older individuals may provide the individualized comfort and assistance that is so important to well being.

The family is the primary support for most older people but without a structure that provides necessary assistance, plus an adequate social services system and more fully developed system of other support, the family may not be able to fulfill its role of major caregiver.

B. SOCIAL SERVICES

In order to provide a full complement of services, natural caregivers and organized social service systems become interrelated in a variety of ways to provide for the needs of older people.

Historically, the family was able to provide the major portion of caregiving without outside assistance. Following the Industrial Revolution, social and economic changes, such as differences in work patterns, changes in standards of living, and establishment of age 65 as the mandatory retirement age, had a dramatic effect on the family and its ability to provide single-handedly for its older relatives.

The Depression of the 1930's highlighted the severe hardships for the large and growing number of older people. In 1935, Congress responded with the passage of legislation establishing the Social Security program, including both a contributory insurance system and money payments to those in greatest need. In 1962, these financial assistance programs were supplemented by social services legislation. In 1963, President John F. Kennedy sent Congress a special message outlining the socio-economic condition of the older population and proposed legislation that led to the Older Americans Act of 1965. Many of the features of the Act were influenced by the 1961 White House Conference on Aging. The Act has been amended seven times and the 1971 White House Conference on Aging influenced the more recent amendments. These recent amendments place emphasis on streamlining and coordinating services and on specific service priorties.

OLDER AMERCIANS ACT

The basic purpose of the Older Americans Act is to help older persons by providing funds to the states for services, training, and research. These three activities are coordinated through the Administration on Aging. The basic philosophy has continued unchanged through the years:

"Section 301 (a): It is the purpose of this title to encourage and assist state and local agencies to concentrate resources in order to develop greater capacity and foster the development of comprehensive and coordinated services systems to serve older individuals by entering into new cooperative arrangements in each State with state and local agencies, and with the providers of social services, including nutrition services and multipurpose senior centers, for the planning, and for the provision of, social services, nutrition services, and multipurpose senior centers, in order to -

1. secure and maintain maximum independence and dignity in a home environment for older individuals capable of self-care with appropriate supportive services;

2. remove individual and social barriers to economic and personal independence for older individuals; and

3. provide a continuum of care for the vulnerable elderly."

The Act, while not requiring income eligibility criteria, focuses on those older people with the greatest needs, including the poor, minorities, rural elderly, and those with functional dependency.

TITLE XX

Another major step toward providing services for older adults was taken in 1974 when Title XX was included in the Amendments to the Social Security Act. The stated goals of the Title XX (Social Services) programs of the Social Security Act are similar to those of the Older Americans Act. Title XX services are, by statute, goal directed. P.L. 93-617 authorized appropriations - - "For the purpose of encouraging each state as far as practicable under the conditions in that state, to furnish services directed at the goals of - -

1. achieving or maintaining economic self-support to prevent, reduce or eliminate dependency,

2. achieving or maintaining self-sufficiency, including reduction or prevention of dependency,

3. preventing or remedying neglect, abuse or exploitation of children and adults unable to protect their own interests, or preserving, rehabilitating, or reuniting families,

4. preventing or reducing inappropriate institutional care, or other forms of less intensive care, or

5. securing referral or admission for institutional care when other forms of care are not appropriate, or providing services to individuals in institutions."

Title XX funds are allocated to the states on a 75-25 matching formula, with each state having responsibility for developing a package of services.

In spite of the scope and importance of the Title XX objectives, the number of programs and services for the elderly that are adequately funded under Title XX is limited. The federal

requirement is that states fund at least a specific group of mandated services. Furthermore, Title XX has always been inadequatedly funded in relation to need. Although many specialists in social policy advocate broadbased programs for efficient planning, such as Title XX, such programs tend to pit vulnerable groups of people against one another as they compete for resources. It is important to look for ways to coordinate better the services provided to both young and old in a manner that is cost effective and most beneficial to both groups.

Social services for older people constitute an array of programs that have been organized to develop, assist, and maintain the ability of the older person to participate in society. These services can be defined in terms of the problems they are designed to help: to assist when personal and family resources are insufficient to meet the basic needs of adequate shelter, food, and clothing; to secure appropriate health care; to permit the exercise of legal rights and participation in the decision making process; to obtain adequate and satisfying employment; to protect from physical and/or mental abuse, neglect, and debilitating dependency; and to obtain counseling for personal and social problems. Too often this has resulted in fragmentation and lack of coordination. Social services can be provided by governmental or voluntary, sectarian or nonsectarian, profit or non-profit sources. They are organized and provided in a variety of ways and settings. Social service systems should assist families in maintaining and increasing their capacity to perform such family functions as social protection and to meet the basic needs of older members. While much progress has been made in many communities across the country, there are numerous recognized problems with the current social services system as it impacts on the lives of older adults.

1. Social services often can not adequately respond to patterns of client needs, due to funding trends and patterns, and in some cases to meet provider goals.

2. There are insufficient points of entry into the social services delivery system at the local level for all elderly people, regardless of economic or educational status; nor do all points of entry have the capacity to open up the entire system to meet individual needs.

3. Services often are inaccessible and/or insensitive to those who are culturally and linguistically different and there are relatively few specific outreach efforts to locate those who are not easily reached.

4. Decision making about services to the older person do not take sufficiently into account the choices of the older consumers in need and the roles of the family and informal support groups.

5. There is a lack of preventive focus in service planning and design and financing; rather, social services tend to focus on the immediate, often critical situation. Reducing risks and developing individual and community capacity to deal with problems is a preventive strategy that receives too little consideration.

6. Interagency planning and coordination mechanisms are inadequate, resulting in wide variations in human service policies and programs, and many service gaps.

7. The Federal, state and local levels have not yet clearly delineated responsiblity for program standards, social service design, monitoring service delivery, establishing priorities, and the assessment of consumer needs and outcomes.

A major task of the 1981 White House Conference is to review the effectiveness of the complex set of programs already in existence and to chart future directions. As this discussion has indicated, legislation has determined the scope of services, the administrative authority under which they operate, and the funding. The regulations for program operation have become more detailed and stringent. Actually, there needs to be far greater emphasis on opportunities for innovative service programs and flexible service provision to test new ideas, and reassess present methods for meeting the needs of older Americans.

Title XX has increased awareness of the existence of publicly funded social services and of the stake older adults have in the future of these services. Federal dollars are essential, but perhaps there is a better means for designating these dollars for services in local communities, so as to round out programs and services across the continuum of need.

A variety of services and resources exist for older persons. The problem is that there are many gaps and spotty coverage. In addition to the mandates of the Older Americans Act and Title XX of the Social Security Act, there are a wide variety of services provided by the private sector. The public and voluntary sector should work more closely to provide equitable distribution of resources and services.

C. OTHER SUPPORT SYSTEMS

Other support systems are defined as those resources that an individual has available through informal relationships with individuals, groups, and the community. This support helps the person to feel cared for, secure, and loved, and helps the individual become part of a caring environment. This environment not only provides emotional support, but also may include the exchange of goods and services which the

giver and receiver feel are necessary or helpful in independent living. How people help each other can be very different and difficult to understand, since this may involve friends, neighbors, people who work together, religious groups, racial and ethnic groups, a retirement group, or those with whom someone lives.

While families are the major providers of support, and social services are designed to enhance independence, the informal support system is still another system needed by many. Whether one is able to contact a person when necessary, how many people can be contacted, and how often people contact each other are important considerations of an informal social support system. People give different meanings to these contacts, and often the contacts have more than one meaning. For example, people might be given emotional and financial support in a relationship with a neighbor or friend. The strength of the contact between a person or persons depends on how each individual feels about the importance of the contact. The contact may be frequent or infrequent; however, it is important to remember that many contacts between one person and another do not necessarily mean that their relationship is a strong one.

Social support systems are available to people of every age. However, when people become older and need continued help to live as independently as possible in their own community, they must rely on these systems in a more intense way. When family and social services systems are unavailable or inadequate for a variety of reasons, older adults often look to others for help in coping with daily living. Increasingly, older adults must turn to natural supports such as neighbors, friends, religious groups, clubs, and ethnic groups for assistance when they require it. These people become very important in helping and may assume the family role in a different way. For example, an older person's friends and neighbors often give assistance during emergencies and check up on the individual on a regular basis. They become the older person's social community. It has been found that friendships are often even more important than contacts with grown children for high morale in old age, and that friends provide emotional support when an older peer is lonely.

Friends and neighbors can enhance the older adult's sense of security in the community, a most important goal when a person is attempting to maintain independence. Neighbors are best suited to provide immediate assistance, as well as to check regularly on well-being, while friends provide a reference group and needed sociability.

D. ALTERNATIVE APPROACHES TO SOCIAL SUPPORT

A number of new services for older adults have emerged in response to attitudinal, demographic, and economic trends. A continuum of services system that establishes close links and interrelationships among family, social services and other support systems must be made responsible to the needs of older people by including a broad range of services from educational programs, and cultural and recreational activities.

For example, congregate housing and other alternative living arrangements are now providing socialization and economic assistance to many, and multi-purpose senior centers are attempting to meet a variety of social service needs.

CONGREGATE HOUSING

The basic wisdom of congregating services for persons who require some assistance with the tasks of daily living within an elderly housing development is becoming increasingly evident. Congregate housing provides meals, housekeeping and personal assistance to persons who--with these limited services--can continue to live independently. The Congregate Housing Services Program--adopted by the Congress--provides funds to assist housing authorities and non-profit housing sponsors to provide these important services within the housing development. Group homes offer another type of living arrangement that facilitates the delivery of services in an attractive humane setting for some older adults who--otherwise--would live alone or in institutions.

MULTI-PURPOSE SENIOR CENTERS

In many communities, multi-purpose senior centers provide a central location for the delivery of social services, while offering opportunities for cultural, recreational, educational, employment, wellness, and other life-enhancing programs. Within such centers, older people are able both to give and receive the services they need. Older adults are seen as whole persons within the senior center setting, humanizing the social services system. The Congress has wisely called for the designation of senior centers as focal points for the delivery of comprehensive, coordinated, cooperative services to older persons. Senior centers provide a supportive atmosphere and create opportunities for self-help within a caring community.

DAY SERVICES AND RESPITE CARE

As the number of very old persons increases, the need for non-institutional settings for the care of frail older people also increases. Provision of day services in a non-medical setting has emerged as an important development in the care of older persons. Day services programs include three impor-

tant goals for nearly all who have the opportunity to be enrolled. First, a well-designed program offers rehabilitative services to persons whose level of mobility and social interaction can be improved.

The evidence is clear: most frail older persons can make important gains toward more fulfilling lives through day services programs. Additionally, for those whose condition may not permit a rehabilitative program, present levels of well-being can be maintained through an effective day services program. Finally, the day services program provides important respite to care givers who otherwise would soon "burn out" from the burden of caring full time for a very frail older person.

HOMEMAKER-HOME HEALTH AIDE SERVICES

Homemaker-home health aide services are designed to provide a mature, trained, supervised para-professional or allied worker to assist older persons who cannot perform all of the basic tasks of daily living, including personal care. Services performed by homemaker-home health aides include homemaking services, such as cleaning, planning meals and shopping for food, and doing laundry. Personal services include assisting with bathing, taking medications, and assistance with a physical therapy regimen. In addition, homemaker-home health aides offer psychological support and instruction. They teach clients how to cope with a new disability or prevent further illness. Instruction in nutrition and support when the person is depressed and lonely are other aspects of the service. The services vary by type and also by duration, based on careful assessment of changing needs. For example, a person recuperating from an operation or accident might need daily help for two weeks, whereas an older individual with a chronic medical problem might need help for a couple of hours two or three times a week for an indefinite period.

A major detriment to the expanded use of homemaker-home health aide services is the reimbursement limitations for both Medicare and Medicaid. Services that enable older persons to remain in their own homes, prevent institutionalization, preserve the dignity and happiness of the individual, and prevent more costly care in later years, should be greatly expanded.

HOSPICE CARE

Another service system that has received considerable attention during the 1970's is hospice care, a program that provides palliative care, medical relief of pain, supportive services to terminally ill persons, and assistance to their families in adjusting to the individual's illness and death. A central characteristic of hospice care, which makes it unique in the health care and service delivery system field, is that the

family and not just the patient is considered. This philosophy derives from the practical recognition that chronic illness, death and dying, affect the entire family. The community involvement in hospice care is another important feature. Most hospices depend heavily on volunteers for services and the informal support system of friends and neighbors is essential to the hospice concept. This integration of formal and informal services with institutional resources distinguishes hospice programs.

VII. SUMMARY

The conclusion of the Technical Committee on Family, Social Services and Other Support Systems is that for most older persons the family will continue to provide their primary support. The Committee recognizes that families need help, from time to time, to cope with the extraordinary needs of some older people. Nonetheless, it is clear that with help--training, encouragement and financial support--families can continue to provide the foundation for an effective, caring support system.

Because the needs of older people vary, the services they require must also be varied. Social services and other support systems enable older persons to remain in their homes and communities. A community that develops an effective support system, utilizing professionals and volunteers and relying heavily upon older persons themselves, creates an environment for a satisfying life not only for older persons but for people of all ages.

There is no single system that can be considered the sole source of social support. The family of the older person must be strengthened so that it can more adequately utilize social services and other support systems.

Social services under both public and voluntary auspices need to be expanded and coordinated. Informal supports must be increasingly recognized and utilized. All are essential to enhancing the ability of the older person to live a satisfying and independent life.

VIII. RECOMMENDATIONS

Preamble

A public policy must be forged to provide for a coordinated comprehensive continuum of services for older persons linking the

family and other informal support systems with both public and private agencies. While acknowledging the substantial contribution of the family and others in providing essential services, there must be equitable and adequate public and voluntary resources in order for such a policy to be fully implemented. Standards must be established and effectively monitored, and provisions made for education and support of care givers.

To accomplish these goals the committee recommends:

1. ECONOMIC SECURITY

   In order to achieve fuller, continuing independent lives for older adults, an income floor at a level consistent with maintenance of health and dignity must be established.

2. SOCIAL SERVICES, INFORMAL SUPPORTS AND THE FAMILY

   Public policy must take into account the contribution and role of the informal supports, the family, and the formal social service system which enable older persons to maintain their independence. In addition, current disincentives in law and regulation with respect to family care and support of older persons must be eliminated.

3. IN-HOME AND COMMUNITY BASED SERVICES

   Public policy should provide for a full range of in-home and community based services as an entitlement for older persons in recognition of the rights and desires of most older individuals to remain in their own homes. Legislation must provide adequate funding for in-home and community-based servcies, including compensation for families and others that provide such support.

4. LINKAGES, ACCESS AND FOLLOW-UP

   Linkages and cooperative relationships among the various social services and other support systems should be organized so that, regardless of point of entry, the older person will have access to, and assurance of, adequate follow-up services.

5. DIVERSITY AND CHOICE

   In designing and implementing social service and benefit entitlement programs, special attention should be given to the diversities of family and cultural patterns that exist among population groups. Options should be available so that older persons can exercise their right of choice with respect to decisions affecting their daily lives.

6. PREVENTION, WELLNESS AND INDEPENDENCE

To promote independence, and prevent illness, dependence and role loss, public policy must support expansion of wellness programs for older adults.

7. NEWER SERVICE PROGRAMS

Critical attention must be given to newer service programs, such as respite care, day care, homemaker-home health aide services, congregate and other group living arrangements, and hospice care for the terminally ill and their families.

COMMITTEE PROCEDURES

The Family, Social Services and Other Support Systems Technical Committee was charged with the responsibility for providing documentation about the state of these systems, short term and long term goals, and policy recommendations that impact on the well being of older people.

The Committee scheduled the first meeting on August 4, 1980, in Washington, D.C., and at that time developed a workplan/outline for the technical report to be submitted in February, 1981. At the next meeting, held in Washington on September 28-29, 1980, the Committee divided into working sub-committees, each group assuming the responsibility for a draft for a particular content area, i.e. family, social services and other support systems. The meeting on December 4-5, 1980 in Washington, was again a working session designed to review materials and finalize the content areas of the paper. The final meeting of the entire Committee on January 15, 1981, in Washington had as its purpose the preparation of the Executive Summary and approval of the revised draft of the report. Subcommittees were given responsibility for the editing of the Executive Summary and the Final Report.

The Committee expresses appreciation to Phyllis Miller, Ph.D. for the writing of the report.

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APPENDIX

FAMILY, SOCIAL SERVICES, AND OTHER SUPPORT SYSTEMS

January, 1981

I. INTRODUCTION

The enclosed material is limited to a selective citation of facts which are directly related to the recommendations developed by the 1981 White House Conference on Aging Technical Committee on Family, Social Services, and Other Support Systems.

The material, separate from the policy paper prepared by the technical committee, is designed to provide additional documentation in support of the eight recommendations developed by the committee.

All of the recommendations are cited at the beginning. They are followed by a series of facts and quotes with appropriate references and citations.

This information contains no narrative or analysis and is limited to quotes and citations supporting each recommendation developed by the technical committee.

1. ECONOMIC SECURITY

RECOMMENDATION: "In order to achieve fuller, continuing independent lives for older adults, an income floor at a level consistent with maintenance of health and dignity must be established."

FACTS & QUOTES

Family Support Disincentives

*Supplemental Security Income recipients are docked one-third of their monthly payments if they live in another person's household. Under such circumstances, they are considered to be receiving "in kind" assistance. (1)

*While parents are financially responsible for providing care for youngsters, adult children are not financially responsible for their parents. (2)

*The current federal Dependent Care Credit provides tax exemptions for working parents who pay for child care and for the care of physically and mentally disabled dependents. However, out-of-home care exemptions are only available for children 14 and under. The exemption discourages families from using community-based care for the disabled elderly. Further, tax credits do not help poor families who through exemptions and/or income are excluded from paying federal income tax. (3)

Barriers to Health Care

*Medicaid, the largest government program providing payment for long term care, is heavily weighted toward nursing home care. The poor and chronically ill elderly must enter a nursing home to receive adequate levels of care. (4)

*In 1978, $7.2 billion in Medicaid money was spent on nursing home care while only about $ 211 million was expended on in-home care. Many families who exhaust their personal, social, and financial resources seek nursing home care as a last resort. (5)

*States have leeway in determining payment levels and methods to use in paying for home health reimbursements under Medicaid. Many states have chosen to be restrictive to curb costs. Some allow only one physician visit a month. When a state sets the reimbursements too low, home health agencies often refuse Medicaid patients. (6)

Lack of Income

*Supplemental Security Income was designed to remove the elderly from poverty. However, federal assistance levels are not high enough, and only in states that supplement federal levels sufficiently is the antipoverty purpose achieved. (7)

"Practically all of the industrialized nations, except the United States and Canada, provide a constant attendance allowance or similar substitute under their old age and invalidity (disability) insurance programs." (8)

2. SOCIAL SERVICES, INFORMAL SUPPORTS, AND THE FAMILY

RECOMMENDATION: "Public policy should recognize the contributions and role of the informal supports, the family, and the formal social service system which enable older persons to maintain their independence with recompense for services as appropriate. In addition, current disincentives in law and regulation with respect to family care and support of older persons must be eliminated."

FACTS

Family and Informal Support Contributions

*Relatives of elderly persons provided 80% of the in-home care to persons 55 and older between 1966 and 1968.(9)

*Daughters, sisters, nieces, or other female kin provide 80% of the in-home care in America. (10)

*A 1975 Cleveland study showed that it costs $6,617 a year to meet the following six levels of care for the noninstitutionalized elderly: financial, medical, compensatory (assistance with daily tasks in the home), social, recreational (caregiving--someone nearby to assist in care of sickness or disability), and developmental (education and employment assistance). Families and friends provided $2,001 while federal, state, local, and private agencies provided $4,615. (11)

*Families and friends expended $46 billion in 1975 to provide six levels of care to the 21 million noninstitutionalized elderly in America. (12)

*While only about 10% of the elderly currently live with their children, nearly 75% of all elderly parents live within a half hour drive of at least one child, and frequent visits are reported. (13)

*Nearly 80% of adult couples surveyed in 1979 said they would be willing to care for an older person in their home. (14)

Formal Social Service Support System

*Medicare and Medicaid provide limited amounts of home health care funding and do not provide needed social services supports such as Meals on Wheels, homemaker services, transportation, and friendly visitors. (15)

*Federal, state, and local governments spent $97 billion on non-institutional care for the elderly in America in 1975. The largest share, $61.8 billion went toward financial assistance; $20 billion for medical assistance; $12.1 billion for help with routine daily tasks; and $1.8 billion for social and recreational assistance. (16)

*The bureaucratic components of the aging network--the public, private, and voluntary service agencies that provide services to the elderly-- often become caught up in turf battles in an effort to sustain and expand their programs. This further compounds the essential coordination of service delivery. (17)

3. IN-HOME AND COMMUNITY-BASED SERVICES

RECOMMENDATION: "Public policy should provide a range of in-home and community-based services as an entitlement for older persons in recognition of the right and desires of most older individuals to remain in their own homes. Legislation must provide adequate funding for such in-home and community-based services, including compensation for families and others that provide such support."

FACTS

Need for In-Home and Community Services

'85% of elderly Florida residents surveyed who suffered chronic health problems preferred living in their own homes as opposed to institutions. The survey that supported these fundings was done among elderly in communities and in nursing homes. (18)

'Many elderly resist nursing home placement because they fear loss of independence, and it often means they must give up their life-long possessions and sever their community ties. Others perceive institutionalization as a prelude to death. (19)

'Several states and local communities have established community demonstration projects and small-scale permanent programs designed to reduce avoidable institutionalization. States and localities have their effectiveness within the existing system of financing and delivering long-term care. (20)

'Noninstitutional care is not only desired, it is more economical to the elderly who are not "greatly" or "extremely" impaired. A New York "Nursing Homes Without Walls" program saves patients about $566 a month over long-term institutional care. The program costs a patient $785 a month. (21)

*A Maryland Demonstration Project showed it cost $555 to $873 a month less for community-based and home care versus institutional care. (22)

*An older person's living arrangement has much to do with the type of health care he or she receives. The Cleveland study showed that 54% of the "extremely" or "greatly" impaired elderly who resided with a spouse or child did not enter an institution. (23)

*In many areas, particularly rural ones, community-based long-term care services are nonexistent or are in short supply. Several local research and demonstration projects designed to provide the elderly with a coordinated package of home-based long-term care services as an alternative to nursing homes discover that they must first develop and expand the number and type of services available in the area. (24)

Poor Elderly Cannot Get Into Nursing Homes

*A New York investigation showed many nursing homes try hard to accept only the relatively well-to-do and private paying applicants, making it difficult for Medicaid-supported and highly impaired applicants to find a bed. (25)

*A Pennsylvania study showed that in six counties where there was a shortage of nursing home beds, nursing home administrators favored

private paying patients. Those on waiting lists were the indigent. (26)

4. LINKAGES, ACCESS, AND FOLLOW-UP

RECOMMENDATION: "Linkages and cooperative relationships among the various social services and other support systems should be organized so that regardless of point of entry, the older person will have access to, and assurance of, adequate follow-up services."

FACTS

Poor Linkages Stifle Access

*The chronically impaired elderly may have to apply separately for Medicaid, Title XX homemaker services, Meals on Wheels, transportation, and visiting nurse services. Typically, each agency will conduct an individual assessment of the client's eligibility for its services. Efforts to arrange home-based care may fail because the client is found ineligible for one or more of the services. (27)

*The percentage of physicians who refer individuals to community services is low, according to a Texas study. Only 21% of home health agency clients, 8% of homemaker/chore agency clients, and 5% of nutrition agency clients were referred by physicians. (28)

*A Massachusetts study suggests that because most physicians are not formally trained in community health or geriatrics while in medical school, they are disinterested and unknowledgeable about community-based care. (29)

Information and Referral

*A General Accounting Office study said information and referral services designed to assist clients in locating services appropriate to their needs have become part of the maze they were supposed to penetrate because their services are fragmented, uncoordinated, and targeted on specific services or clientele groups. (30)

*In a study done for the U.S. Department of Health, Education, and Welfare, a random number of information and referral providers were interviewed, 94% interviewed said they made linkages between users and providers which was confirmed by the providers. I & R centers made appointments with providers if users were incapable of calling for themselves. 90% of the information and referral services indicated linkages were appropriate, but needed services were not always available. Only 13% of the provider agencies contacted said they could occasionally serve users. (31)

Other Linkage

*Area Agencies on Aging, created by 1973 Amendments to the Older Americans Act, are responsible for planning and coordinating service systems designed to meet the needs of older persons within a specific geographic area. There are more than 580 area agencies in the United States. They also grant federal funds to private and public agencies who deliver services to older Americans. (32)

5. DIVERSITY AND CHOICE

RECOMMENDATION: "In designing and implementing social service and benefit entitlement programs, special attention should be given to the design to the diversities of family and cultural patterns that exist among population groups. Options should be available so that older persons can exercise their right of choice with respect to decisions affecting their daily lives."

FACT & QUOTES

"The ways in which people of different ethnic backgrounds perceive family boundaries, responsibilities, and expectations vary greatly and affect the patterns of help and social and emotional support across generations and between kin." (33)

"To be fair to Americans of all backgrounds, policies and programs need to be varied and flexible." (34)

"Alternatives which are appropriate to the value and needs of Americans of all cultural backgrounds should be available." (35)

"In the development of federal, state, and local policies and the implementation of programs and services of concern to minority elderly, it is necessary to consider these cultural diversities." (36)

"People grow old in very different ways, and the range of differences--whether biological, psychological, or social--becomes greater, not narrower, with the passage of lifetime. There are striking differences between the sexes and among the ethnic and socio-economic groups, to say nothing of the many other factors that produce diversity, with a result that 60-year-olds or 80-year-olds are very heterogeneous groups." (37)

"The differing values of the service provider and the consumer can result in culturally incompatible services that are inaccessible to the ethnic client." (38)

6. PREVENTION, WELLNESS, AND INDEPENDENCE

RECOMMENDATION: "To promote independence, and prevent illness, dependence and role loss, public policy must support expansion of wellness programs for older adults."

FACTS & QUOTES

Independence

"The Bicentennial Charter of Older Americans emphasizes the rights of older adults, including the right to ready access to services that enhance independence and well-being, yet provide protection and care as needed." (39)

"Absence of opportunity to choose among care and service options--as well as to participate in everyday tasks and decisions--is likely to produce apathy and accelerate dependency. This opportunity for choice not only promotes health, it also helps preserve individual dignity and sense of worth." (40)

"The road to maximum independence is often paved with supports of various types." (41)

Functional Roles

"It is indefensible to continue a situation where we fail to match up millions of older people who want to serve with the critical community needs that could be met by systematically enlisting their help." (42)

Intergenerational Relationships

"Available research indicates there is evidence that intergenerational interaction tends to soften or significantly change negative stereotypes and attitudes of one group toward the other." (43)

7. NEWER SERVICE PROGRAMS

RECOMMENDATION: "Critical attention must be given to the newer service programs, such as respite care, day care, congregate and other group living arrangements, and hospice care for the terminally ill and their families."

Financing

"The amount of funds needed to establish a hospice is related to the types of services provided. The highest need is associated with those providing inpatient services in new facilities; the second highest, with those providing only home-based services. Operating costs are similarly related to the types of services provided." (44)

Forecasting Need

"The National Cancer Institute (NCI) reported that 387,430 persons died from cancer in 1977, 60% of whom were 65 years of age or older. Thus, since hospices were primarily serving cancer patients, the potential population that hospices could serve is about 400,000 persons per year." (45)

Cost Savings

"Any cost savings available from the hospice concept would appear to depend on the ability of hospices to care for patients at a lower level of care (home health instead of skilled nursing facility or skilled nursing facility instead of inpatient hospital)." (46)

"A study by the Rochester, New York, Blue Cross plan of home care provided through hospice disclosed that "the average daily cost of round-the-clock care provided to terminally ill patients in 1978 was $85.75; less than the $200 daily cost of hospital care." (47)

"With patients and their families as partners in their own care, costs can be further reduced. It has therefore been estimated that even if costs in a hospice facility were as high as $102 a day, as compared to $200 a day at a New Haven, Connecticut, hospital, the nation's insurance bill for terminally ill patients could be reduced by one-third to one-half, with a resultant saving of billions of dollars." (48)

Bereavement Services and Human and Cost Implications

"An expert on bereavement has demonstrated that significant savings on costs for psychiatric care and mental hospitals for survivors can be achieved by preventive counseling with the bereaved, an important aspect of the total hospice program. The cost of untreated bereavement to the community also included drugs like tranquilizers, as well as alcohol. It has been found that proper bereavement counseling at the right moment can reduce other medical costs among survivors." (49)

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Retirement Income
Health Maintenance and Health Promotion
Health Services
Social and Health Aspects of Long Term Care
Family, Social Services and Other Support Systems
The Physical and Social Environment and Quality of Life
Older Americans as A Growing National Resource
Employment
Creating an Age Integrated Society: Implications for Societal Institutions
Creating an Age Integrated Society: Implications for the Economy
Creating an Age Integrated Society: Implications for the Educational Systems
Creating an Age Integrated Society: Implications for Spiritual Well-Being
Creating an Age Integrated Society: Implications for the Family
Creating an Age Integrated Society: Implications for the Media
Creating an Age Integrated Society: Implications for Governmental Structures
Research in Aging

Experts from various fields were appointed by the Secretary of Health and Human Services to serve on 16 Technical Committees, each charged with developing issues and recommendations in a particular area for consideration as background material for the delegates to the 1981 White House Conference on Aging.